Palliative Approach in Dementia Care
Delta Hospital Pilot Study

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Dementia is a progressive terminal illness for which there is no cure.

Studies found that dementia is not viewed as a terminal illness (Sampson, 2006; Mitchell, 2004; Morrison & Siu, 2002).
Ambiguous Dying
Frameworks

BC Dementia Service Framework

<table>
<thead>
<tr>
<th>LEVELS OF HEALTH STATUS</th>
<th>STAYING HEALTHY</th>
<th>GETTING BETTER</th>
<th>LIVING WITH ILLNESS</th>
<th>END OF LIFE</th>
</tr>
</thead>
<tbody>
<tr>
<td>INDIVIDUAL</td>
<td>Goals and Recommendations</td>
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<td>CARE PROVIDER</td>
<td>Goals and Recommendations</td>
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<td>SUPPORT SYSTEMS</td>
<td>Goals and Recommendations</td>
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<td>HEALTH CARE ENVIRONMENT</td>
<td>Goals and Recommendations</td>
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A Model to Guide Hospice Palliative Care:
Based on National Principles and Norms of Practice

Canadian Hospice Palliative Care Association
March 2002
Assumptions

- Palliative care ought to be a core competency when caring for people with dementia.

- Quality of care for people living and dying with dementia will improve when caregivers’ knowledge, confidence and skill increase.
Will a 4 hour interdisciplinary workshop:

- Raise **awareness** of dementia as a progressive illness?
- Increase staff **confidence**, **skill** and **knowledge** to meet the needs of people living and dying with dementia and their families?
- Encourage **strategies** to be incorporated into daily care?
Participants n=60

- Interprofessional (RN, RPN, OT, PT, RCA, SW)
- Varied roles (direct care providers, managers, educators)
- Acute and residential complex care
Pilot Development

- Literature review
- Curriculum from *Caring Journey: Better care, Better life for people with dementia* & *Hospice Palliative Care Basic and Enhanced days*
- Fraser Health best practice guidelines
- Focus groups (family & leaders)
- Refined workshop based on feedback
Workshop Content

- Person with dementia
- Family of person with dementia
Jeopardy
EVALUATION

- Identify challenges at start of session
- Satisfaction survey
  - Quantitative (excellent/very good/good/fair/poor)
- Knowledge pre test/ post test
  - Multiple choice/ True & False
- Self evaluation
  - Qualitative (I learned that…)
- Family feedback
- Leadership feedback
## Findings

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<tbody>
<tr>
<td><strong>Staff satisfied</strong></td>
<td>Rated very good-excellent</td>
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<tr>
<td><strong>Knowledge increased</strong></td>
<td>↑10%</td>
</tr>
<tr>
<td><strong>Confidence increased</strong></td>
<td>1-10 scale</td>
</tr>
<tr>
<td></td>
<td>↑ 7.2 - 8.3</td>
</tr>
<tr>
<td><strong>Attitudes challenged</strong></td>
<td>“… they are needy families, not difficult”</td>
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<tr>
<td><strong>Awareness raised</strong></td>
<td>“Inform family dementia is a progressive disease”</td>
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<tr>
<td><strong>Compassion triggered</strong></td>
<td>“Put yourself in their reality”</td>
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</table>
Theme one: I can connect with and comfort the person with dementia.

“Don’t under value the 30 seconds you spend with someone - residents live in the moment.”

“Enter into the patient’s reality and emotion.”

“Changes in resident could be pain!! Behaviours have meaning.”
Theme two: *I can talk about death and dying.*

“Palliative care starts when clients enter residential care with dementia.”

“Initiate conversations re frailty/dying with a family member.”

“It is okay to talk about dying with family members.”
Theme three: *Families need my care too.*

“Be more patient, think more about where they [family] are coming from.”

“Family knows the person best - we know dementia the best. Families want to teach us how to care for their loved one.”

“Be honest.”
Theme four: A *palliative approach* takes a team

“Work to have family’s voice heard - don’t want to repeat stories over and over.”

“Encourage nurses and care staff to have advanced care planning in place.”

“As a team approach we need to communicate much better - be more comforting.”
Moving Knowledge to Practice

Practice Change

↑Awareness
↑Confidence
↑Knowledge
Implications

- Build dementia and palliative care as core competencies for nursing staff working in residential care and medical units.
  - Develop a strategy to spread this workshop and sustain change in behaviour.
  - Offer as interdisciplinary, intersectoral education
Further research:

- What competencies in dementia care do health professionals possess and what areas require improvement to deliver a palliative approach?
Further Reading


- Manning, Doug. *Share my Lonesome Valley*. 
Comments?